(Under)treatment of pain in dementia

Plooij, B.

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Chapter 8

Summary and General Discussion

In this thesis issues concerning both undertreatment and treatment of pain in dementia patients are discussed. These issues include under-exposed features of undertreatment of pain in dementia patients, suggestions for additional pain assessment methods, suggestions for pain treatment, and an evaluation of the (positive) effects of adequate pain assessment and treatment in dementia.

Undertreatment of pain

Although undertreatment of pain has been widely recognised in the last years (Scherder et al., 2005; Achterberg et al., 2007; Husebo et al., 2008), it is quite unfortunate that it is still a relevant problem nowadays (Plooij et al., 2012). The general view is that undertreatment of pain in dementia patients, compared to non-demented older people, is due to changes in communicative problems. Communicative problems are present in all major dementia subtypes, i.e. Alzheimer's disease (AD; Taler and Phillips, 2008), frontotemporal dementia (FTD; Reilly et al., 2010), and vascular dementia (VaD; Reilly et al., 2010), and might hamper a patient's ability to indicate pain (Scherder et al., 2005). It has been suggested that owing to the degenerative nature of diseases causing dementia, resulting in further decrease of cognitive functioning with disease progression (Burns et al., 1991), the ability to indicate pain will decrease further, resulting in increased undertreatment of pain (Closs et al., 2004; Allen et al., 2003). However, findings concerning the relationship between (under)treatment of pain and cognitive functions are ambiguous (Fisher et al., 2002). A striking feature of these studies is that not all participants suffered from a painful condition, which may have influenced the relationship between cognitive functioning and pain medication. Therefore we investigated the relationship between pain medication prescription and cognitive functioning in dementia patients with known painful conditions **(chapter 6).**

The results of this study show no relationship between global cognitive functioning and pain medication in the total group of nursing home residents with dementia with at least one painful condition. Also, in a subgroup of patients with Alzheimer's disease no such relationship was present. Additionally, it is alarming that of the dementia patients that were

able to report pain, and did report pain, more than 40% were not receiving pain medication. Undertreatment of pain seems to be independent of the cognitive impairment; even dementia patients with relatively mild cognitive disorders, who might still be able to communicate about pain, are at risk. Hence, an important lesson that can be learned from the present study is that purely the diagnosis 'dementia' is a risk factor for inadequate pain treatment.

The findings that even dementia patients who are able to communicate about pain are at risk for undertreatment stresses the importance to be aware of other signs that may indicate pain. We argue that one should be aware of physical inactivity as a sign of pain in older people with and without dementia. Although in many observational scales used for pain assessment physical activity is a sign of pain, e.g. distressed pacing in the PAINAD (Warden et al., 2003), and restlessness in the PACSLAC (Fuchs-Lacelle and Hadjistavropoulus, 2004), the DOLOPLUS2 (Wary, 1999), and the DS-DAT (Hurley et al., 1992), both aging (Johannsen et al., 2008) and an increase in the number of chronic painful conditions (Issa & Sharma, 2006; Tsang et al., 2008) are associated with physical *inactivity*. In **chapter 2** we therefore reviewed studies that investigated the relationship between pain and physical inactivity in older people with and without dementia. The results showed that in older persons without dementia, a positive relationship between physical inactivity and pain has been demonstrated, i.e. more pain is associated with more physical inactivity. A causal relationship between pain and physical inactivity, i.e. pain may cause physical inactivity, is supported only by older persons' own comments. In persons with dementia, the few available studies suggest that pain may cause physical inactivity and vice versa. Awareness by the nursing staff that physical inactivity might indicate pain in older people with or without dementia may reduce the risk of undertreatment of pain. In turn, early acknowledgement of pain by the nursing staff and subsequent adequate pain treatment may reduce the level of physical inactivity.

Pain assessment

Early detection of pain in dementia patients may result in adequate pain treatment. However, despite the availability of many self-report and observational pain scales undertreatment of pain in dementia is still common (Plooij et al., 2012). A factor complicating pain assessment might be that although dementia patients are still able to perceive the presence of pain, they may have difficulty understanding the sensation and placing it in context (Scherder et al., 2005). This may explain why dementia patients express their pain different than older people without dementia (Herr and Dekker, 2004), and hence why pain in dementia patients is hard to identify by caregivers. These findings stress the need for more adequate, objective pain assessment methods. As patients with dementia may even experience an increase in motivational/affective aspect of pain, owing to white matter lesions present in all major dementia subtypes (De Reuck et al., 2011), the development of reliable indicators specifically for motivational/affective pain would be clinically most relevant.

The study described in **chapter 5** examined the relationship between pain tolerance and cognitive functioning, in order to investigate whether neuropsychological testing may contribute to pain assessment. Examining this relationship in healthy people is the first step in eventually understanding this relationship in dementia patients. This relationship was expected to be present based on overlap in brain areas that are involved in both the medial pain system, involved in the motivational affective component of pain (Scherder et al., 2003), and various cognitive functions, i.e. memory (hippocampus) (Burgess et al., 2002), attention (anterior cingulate cortex) (Bush et al., 2000), and executive functioning (prefrontal cortex) (Elliot, 2003; Jurado and Roselli, 2007). The results showed that pain tolerance and pain tolerance corrected for threshold were both related to sex, executive functioning, and attention. Linear regression analyses revealed that only EF contributed significantly to the total explained variance of both Pain tolerance and Pain tolerance corrected for threshold. These findings imply that in healthy adults, including older people, reduced performance on neuropsychological tests that measure executive functions may indicate that the pain tolerance is reduced, and that less pain intensity may lead to suffering. Future research in various dementia

subtypes is needed to examine the usefulness of tests for executive functioning as an objective addition to existing pain assessment methods.

An objective method to assess pain that has been used in children and adolescents is the registration of autonomic responses to pain (Storm, 2008), e.g. changes in skin conductance, changes in blood pressure, or changes in heart rate (Katz and Melzack, 1999). In **chapter 3** studies on autonomic responses in older people and dementia patients were reviewed. Results from the experimental studies reviewed showed that, although autonomic responses to pain may be attenuated, they are present in older people and in dementia patients. In reaction to severe pain blood pressure responses are even unaffected in AD. Experimental studies on autonomic responses to pain were not available for the other dementia subtypes, but data on neuropathological changes suggest that, similar to AD, most autonomic responses to pain may be reduced in FTD and VaD. More specifically, in FTD skin conductance responses may be even more affected, compared to AD. Additionally, neuropathological data suggest that in VaD blood pressure responses may in turn be increased. These findings imply that autonomic responses can be used to evaluate pain treatment in a single patient. More specifically, the presence of autonomic responses may be indicative for the presence of pain in older people and in dementia patients. However, one must be aware that the absence of autonomic responses does not necessarily indicate the absence of pain. For example, owing to the use of cardiovascular medication, such as β–blockers and calcium channel blockers, frequently used by older people (Lord et al., 2003), specific autonomic responses in reaction to pain, i.e., increased blood pressure and increased heart rate, may be reduced or even absent.

Autonomic responses to central neuropathic pain have not yet been studied before. This would be relevant, as central neuropathic pain may be the most undertreated type of pain in patients with dementia. Improved assessment of pain, including central neuropathic pain is necessary for adequate pain treatment, and hence for reducing or terminating undertreatment of pain in dementia.

Pain treatment

Very little attention has been paid to 'central' pain that may occur in various subtypes of dementia. We argue that central neuropathic pain may be the most undertreated type of pain in patients with dementia, as the medical staff is less familiar with this type of pain. Appropriate assessment of this type of pain is clinically relevant, as it requires treatment that differs from treatment of other types of pain. In **chapter 4** firstly central neuropathic pain in stroke patients and its possible presence in dementia was briefly discussed. Subsequently, methods for pain assessment and pain management, with a special focus on central neuropathic pain, were reviewed. The results showed that insight into the *type* of pain contributes to a more effective pain treatment. For example, paracetamol has no direct effect on central neuropathic pain. Anti-depressants and anti-convulsants should be taken into consideration when treating central neuropathic pain. The prescription of antiepileptic drugs in general requires cautiousness considering the adverse effects, e.g. dizziness, drowsiness, and weight gain (Perucca et al., 2006; Siniscalchi et al., 2012). In patients with dementia, prescription requires even more cautiousness considering the negative effect of these drugs on cognitive functions, although not all antiepileptic drugs influence cognition to the same extent (Knegtering et al., 1994; Mendez and Lim, 2003). Other adverse effects of antiepileptic drugs in dementia include a confused state, ataxia, deterioration in visual functions, and cardiac arrhythmias (Mendez and Lim, 2003).

Although paracetamol has no direct effect on central neuropathic pain, it may affect peripheral discomfort, and hence reduce allodynia (an important characteristic of neuropathic pain, meaning that the patient experiences severe pain that is provoked by sensory stimuli that are normally not painful at all, e.g. light touch or a thermal stimulus) (Haanpää and Hietaharju, 2010). Therefore we suggest that when pain is suspected, irrespective of its aetiology pain treatment starts with paracetamol.

Effect of pain treatment

Finally, a longitudinal intervention study examined the effect of the implementation of structured daily pain assessment on undertreatment of pain in dementia patients, and on their cognitive functioning **(chapter 7)**. In that study, the Dutch version of the Pain Assessment Checklist for Seniors with Limited Abilities to Communicate (PACSLAC-D; Zwakhalen et al., 2007) was implemented as pain assessment in the routine daily care in Dutch nursing homes. The study showed that the number of participants that had pain medication prescribed did not structurally increase due to the intervention. However, the changes in the proportion of people that have paracetamol and opioids prescribed, compared to the constant proportion of participants in the control group, suggest a more active pain medication policy in the nursing homes participating in the intervention. Additionally and most importantly, the results showed that global cognitive functioning (measured with the MMSE) decreased significantly less over a period of nine months in the residents who underwent structured pain assessment, compared to residents who received unadjusted care. Also the performance on the Digit Span Backward dropt significantly more in participants from the control group, compared to the intervention group. No interaction effects were present for the other cognitive tasks. A far as we know this is the first study that examined the effect of structured pain assessment, and hence more adequate pain treatment, on cognitive functions in dementia patients. Because in this study the intervention, i.e. pain assessment, was executed by the nurses, and not by the researches, this type of intervention can probably be successfully implemented in other nursing homes.

Implications and recommendations

The studies described in this thesis emphasize that after approximately 20 years of research, we are still at the beginning of understanding pain in dementia. Increasing the knowledge about undertreatment, for example that also relatively good functioning dementia patients are at high risk **(chapter 6)**, and that physical inactivity may be a symptom of pain in dementia patients **(chapter2)**, will contribute to pain detection.

Also the development of objective, reliable tools for pain assessment is essential in reducing undertreatment of pain in dementia. At this moment, the perfect tool for pain assessment in dementia patients does not exist. The available tools all have their limitations, i.e. self-report pain scales are only applicable in dementia patients with satisfactory levels of communication to understand the tools; pain observation scales face the problem of subjectivity. In this thesis suggestions were made for two alternative methods for pain assessment in dementia patients, i.e. registration of changes in autonomic responses **(chapter 3)**, and the use of neuropsychological tests **(chapter 5)**. However, these were just preliminary studies that explored the possibilities of these methods. Further research is needed to develop these, and other, methods for pain assessment, and to study the usability of these new methods in clinical practice. For the time being, a combination of self-report pain rating scales and observation scales should be applied; of course, the patient's understanding of the meaning of the self-report rating scales is a prerequisite **(chapter 4)**.

Although it was shown in this thesis that implementation of a pain observation scale in routine daily care of nursing homes may improve pain treatment, and subsequently the cognitive functioning of the dementia patient **(chapter 7)**, the implementation was not without difficulties. Based on conversations with nurses some recommendations can be made for improving the implementation of structured daily pain assessment in nursing homes.

Firstly, the nurses indicated that they felt that the application of the observational scale was time-consuming. Observation of the patients can take place during routine daily care, and filling in the score sheet should take only a few minutes extra. However, in the first period of the intervention, a period in which the nurses were getting used to the observational scale, it indeed was time-consuming. This caused resistance in some of the nurses to use the observational scale each day. We argue however that in order to make pain assessment a part of the routine care, the observational scale should be used daily, without exceptions. The nurses did admit that by the time they became more and more familiar with the observational scale, and knew the items of the scale by heart, the

scoring of the scale was easy and quick. Therefore we would stress that some extra 'hands on the bedside' should really contribute to the first stage of the implementation. A second problem with compliance of some of the nurses was that they saw the intervention as a temporary project, instead of a new part of their routine daily care. The cause for this temporary character of the implementation was that it was linked to a scientific evaluation of a restricted period. To improve compliance and to make the implementation successful it has been proven valuable to have one nurse at each ward who is responsible for monitoring the implementation and who ensures that the observations really take place. A person within the organisation who is responsible for the implementation, instead of an external researcher, strengthens the implementation as part of the organisation's routine daily care.

As stated in **chapter 7**, pain assessment itself is not enough to improve cognitive functioning. The findings of the pain assessments must be communicated to the nursing home physician, who will than start pain treatment if appropriate. This stresses the importance of discussing the pain assessment scores at least once per week, which could best be done at a fixed moment, for example as part of the weekly multi-disciplinary meeting.

Additionally, we recommend structural pain assessment from the first moment a patient moves into a nursing home, as part of the regular intake procedures. This is especially important as the cognitive abilities, and hence the ability to communicate about pain, may still be relatively good at admission, but show acceleration in the rate of decline after moving into a nursing home (Wilson et al., 2007). Pain assessment at admission provides a base-line measurement, which helps evaluating future measurements. In our opinion, pro-active pain assessment is better than to intervene when behavioural changes may indicate pain, because in the latter case the pain probably exists already for a while.

Fortunately, the present study is not the only study that focuses on the reduction of pain in dementia patients. For example, recently another most promising project has started to evaluate the implementation of a stepwise approach in detecting and reducing pain and challenging behaviour in

nursing home residents with advanced dementia (STA OP!, an adjusted Dutch version of the Serial Trial Intervention)(Pieper et al., 2011). The more initiatives to reduce pain in dementia patients, the better!

Besides dementia patients, other groups of people may be at increased risk for undertreatment of pain as well, for example those who suffer from intellectual disabilities, such as Down syndrome. A recent review of the literature about pain in adults with intellectual disabilities concluded that clinical pain studies with persons with intellectual disabilities are lacking, despite the high incidence of painful conditions in people with intellectual disabilities (De Knegt and Scherder, 2011). Additionally, the review showed that people with Down syndrome might experience intense pain from a hot object while being less able to express a verbal response quickly enough to avoid burns. These findings imply that also in people with intellectual disabilities attention to pain and adequate pain treatment is very important and needs more attention.

Conclusion

In conclusion, this thesis provides evidence that undertreatment of pain in dementia patients is still a major problem. Some suggestions have been made to improve pain assessment and pain treatment in this population. Although there are still major steps to take, reducing undertreatment of pain in dementia patients is of utmost clinical relevance.

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